Consumers' views of quality in the consultation and their relevance to 'shared decision-making' approaches

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Abstract

Background There is a recognized need to assess the effects of shared decision-making and other communication interventions. However, the outcomes usually assessed for evidence of 'effectiveness' are determined by researchers and have not been based on consumers' views.

Aim This study aimed to identify the important outcomes of consultations for consumers, and to compare with those reported in the current literature.

Setting and participants Forty-seven participants attending six focus group interviews. Most interviews took place in and all were orientated towards the UK primary care setting.

Methods Focus group study.

Results Many affective outcomes were identified, consistent with the current literature trends. However, many cognitive and behavioural outcomes that are assessed in the current literature were not noted by participants as important. Furthermore, a broader range of outcomes than is evident in the current literature was viewed as important to these participants.

Conclusions There is a need to revisit the outcomes which are assessed in decision-making and communication research. The outcomes of greatest importance to consumers must be identified and confirmed by new research which is based directly on the views of consumers themselves.

Introduction

Greater involvement of consumers in decisions about their treatment or care ('shared decision-making' – SDM) is increasingly advocated.[1] Empirical evidence about the benefits of such approaches is now beginning to accrue.[2–4] However, there is debate about the precise outcomes which should be used to evaluate the benefits (or harms) of involving consumers.[5] The term 'outcomes' is taken to include both true outcomes which can be witnessed at the end of a

consultation, and also outcomes which refer to the process within the consultation. Much of the literature to date has evaluated 'cognitive' outcomes,[6] such as consumers' knowledge or accurate risk perception, and behavioural outcomes such as compliance with treatment.[5,6] Increasingly, the focus is shifting towards more 'affective' outcomes,[6] such as consumer satisfaction with the consultation or the decision made, consumers' anxiety, and their certainty or confidence that the most appropriate treatment has been chosen.[5]

Validated and reliable scales have been developed and are now available for use in the evaluation of some of these affective outcomes.[7–10] Despite this there remains a concern about the extent to which any of these outcomes are really the issues of most importance to consumers. They are the users and the people whose interests should be the principal objective of any health-care provision.

Outcome assessment scales can be developed by reference to existing literature, key informant professionals and consumers.[11,12] The foundation of any scale lies in the identification of the key issues and aspects which must be assessed ('item formulation'). Reports of the development of the most widely accepted outcome assessment scales in SDM-orientated research[8,10] describe how these have been generated in keeping with theoretical constructs[10] or by modifying and testing items related to other instruments.[8] Such processes were also used in the generation of items for other established but broader satisfaction instruments.[13] To be sure that these scales assess the issues of importance to consumers, it is crucial that the consumers' views themselves are specifically sought and explored.

In this study we, therefore, sought to identify the outcomes of importance to consumers by more direct enquiry than has been reported for previous scale developments.[8,10,13,14] We used a qualitative approach to enable participants to identify and explore issues in depth. We sought to identify similarities and differences between the outcomes volunteered in interviews and those frequently assessed in research.[5] In this paper we use the term consumers as synonymous with others such as patients, clients, users of services and so on. We recognize that the appropriateness of the terms may vary according to the precise nature of the situation being considered, but for simplicity and consistency we will confine our terminology to 'consumers'.

Subjects and methods

Method

Six focus group interviews were held in Wales and England between November 1998 and November 1999. Focus group methodology was used to identify group norms or a range of views,[15] and to capitalize on the interaction within the group to elicit rich experiential data.[16]

Study sample

A range of subjects was recruited by purposeful sampling. Five of the six groups comprised a range of consumers, consumer advocates and consumer representatives. These included people invited to take part in the study whilst attending for their health-care at general practices in Wales, volunteers linked with other general practices, and further individuals involved in 'lobbying' consumer representation at wider levels and contributing consumer views to research projects. In addition, one group comprised non-medical individuals with experience in playing roles of consumers ('patient simulators') in medical training.

The groups were as follows (and the number of participants per group, 47 in total):

- One 'Patient participation group' ($n = 8$) from a South Wales group general practice (Swansea area).
- One group of patients ($n = 6$) recruited whilst attending for routine health-care at another South Wales group general practice (Cardiff area).
- One group of patients ($n = 9$) from a South Wales 'single-handed doctor' general practice, comprising members of the 'Patient

Participation Forum' and volunteers from the patient list (Neath area).
- Two UK national consumer representative groups (both convened in London): Patients' Association (Council members, and paid and voluntary staff; $n = 10$) and Consumers Advisory Group for Clinical Trials (Executive and membership individuals; $n = 8$).
- One group of 'patient simulators' ($n = 6$; Cardiff area).

The first three of these groups can be regarded as general practice-based or general practice-convened. The two consumer representative groups were interviewed to seek the views of those more accustomed to being 'consumer advocates'. The last group was closer in nature to the first three, though with experience of specifically considering communication skills. Even so, the purposeful sampling was intended to over-represent those with specific interests, rather than 'the average view'. All individuals connected to these various groups were invited to participate, with the exception of the routine surgery attendees. Sixteen people attending on 1 day indicated consent to participate in this latter group, though only six could attend the scheduled meeting. All the patient simulators attended their scheduled meeting. The attendance rate in the other four groups was approximately half of those eligible to attend.

The interview structure

The participants were provided with an overview of some of the issues and current trends in training and policy regarding the involvement of consumers in decision-making, and given an outline of the focus group interview. Participants listened to an audio-taped consultation as a trigger for the interview to follow. This consultation was an actual consultation from general practice undertaken by one of the authors (AE) in which hormone replacement therapy is considered. The consultation lasted 15 min and explored the harms and benefits of such therapy, using graphical visual aids to portray information.[17]

The interview lasted up to 2 h for each session, and was moderated by one of AE, GE or CS. In semi-structured format, the interview first addressed issues around 'shared decision-making',[18] such as the degree to which participants valued the concept and the degree to which they felt it was implemented in practice. Participants were encouraged to share previous experiences to illustrate issues for the group. The group were invited to comment where they wished, and to identify a consensus or range of views on these issues. Participants were then asked to identify the outcomes which they felt were important to them, or which they felt would be important to other consumers in general. After identifying the principal areas of importance to these participants, specific outcomes commonly encountered in the medical literature were outlined to the groups. Participants commented on the value they placed on these commonly reported outcomes. Fuller details of the interview are contained in Appendix 1.

Analysis and validation

The focus groups were audio-taped for subsequent transcription and analysis. The transcripts were examined by three authors (AE, CS, GE) to identify emergent themes[15] which were then agreed by discussion. All data were then categorized independently by two researchers (AE and GE), again with agreement over classification achieved by discussion.

Results

All the consumer groups expressed broad support for the idea of consumer involvement, though they recalled great variation in practice. Specific themes in the focus group interviews were evident and are described below. In general, consumers indicated that they desired at least some degree of involvement in treatment decisions, though this was frequently not their experience in reality. Some participants expressed satisfaction with current practice, often when decisions were made primarily by

the professional involved. Thus, the concept of 'appropriate involvement' emerged.

Themes

A number of more specific themes and categories were evident from the data as identified in Table 1. These will now be described and illustrated with relevant data. Data are labelled with the focus group from which they are drawn, and are attributed broadly as 'primary care-based' or 'advocate groups'.

Context of discussions in the consultation

A sequence of consultations

Consumers in this study expressed views that they usually regard consultations as part of a series of consultations in which the discussions unfold and progress. To some extent this provides a solution to the problem of lack of time within a single consultation to 'share decisions' fully (see below).

> the consultation is often quite short, but the person comes back for a second phase consultation, the doctor knows what it's going to be about in advance and therefore presumably can prepare a slightly longer session to discuss what he really wants to discuss, even in NHS clinics (PA p10; advocate group)

Continuity with same professional

Given that consultations might be part of a series in which a single problem is addressed, treatment decisions made and progress reviewed, participants placed a high value on continuity of care in such a 'treatment episode'. They felt that consumers frequently have knowledge about the characteristics of the professional as they commence a treatment episode. They may choose a certain style for a particular type of problem. However, during an episode, the participants noted that as consumers they develop greater knowledge about the professional, and vice versa. The product (in the ideal scenario) is that when a decision-making point is reached, the professional 'knows' the needs of consumer, and the consumer has a degree of confidence in and an ability to talk to the professional.

> it works best, the shared decision, if your doctor knows you…. But when they don't know you, it's very difficult to put your point of view over when something has cropped up (PS, p3; primary care-based)

Respect for individual consumer

Some participants indicated that the above scenario can only take place in a context in which the consumer feels respected. They felt

Table 1 The outcomes of importance to consumers – themes and categories identified in the data of these focus groups interviews

Theme	Category
Context of discussions in the consultation	1. A sequence of consultations 2. Continuity with same professional 3. Respect for individual consumer 4. Variable involvement according to context
Process of discussions in the consultation	1. Individual contribution to discussions 2. Perceived involvement in decisions 3. Perceived professional-consumer agreement 4. Satisfaction with the way a decision is made and sufficient time to decide 5. Certainty that best decision made 6. Opportunity to involve others
Content of discussions in the consultation	1. Options and choices specified 2. Information provision 3. Support materials 4. Review arrangements
Health outcomes	1. Anxiety/reassurance little value on adherence or health behaviours *per se*

this was likely to be implicit from the manner of the proceedings, but if not perceived by the consumer then they are unlikely to reach the decision-making stage with the confidence described above.

> people automatically assume you are an imbecile because you are not a medical person but you do know for certain when there is something wrong with you (Cf, p29; primary care-based)

Variable involvement according to context

Developing the concept of 'appropriate involvement', consumers felt that the aim of consultations should not be participation *per se*, but rather the professional should seek involvement *to the level that the consumer desires*. Furthermore, consumers were aware that their own desire for involvement would vary from one situation to another. For example, they envisaged contributing significantly to a treatment decision about a chronic health problem (e.g. hypertension), but in the emergency situation they would prefer (and expect) the professional to take the lead. They would expect the professionals to direct where appropriate, thus using as well as providing their specialist knowledge. If consumers are not accustomed to expect involvement, they also felt that the professionals should give guidance as or when requested.

> I think this is what doctors are trained for … They must judge when it's best to say to the patient "I would recommend this" or he says to the patient 'these are the options you chose between them' and they must be not life-threatening situations (Sw p8; primary care-based)

Process of discussions in the consultation

Individual contribution to discussions

Participants expressed views that they wished to come away from consultations with a feeling of having contributed meaningfully to the discussions. This is perhaps closely linked to the category of 'Respect' above, but refers more specifically to the actual consultation. Many participants expressed a desire to feel that they were on equal terms with the professional, and that their personal values had been taken into account in arriving at a decision on treatment or care.

> I want to be talked to as a person who can make decisions (PS p8; primary care-based)

Perceived involvement in decisions

Participants felt it was important to perceive that they had been involved in the decision-making process. They also recognized that the opportunity for genuine involvement may simply not be offered by the professional, but that the consumer still comes away with a feeling of having made a personal contribution. Where there is dissonance between the *perceived* and the *actual* levels of consumer involvement, these participants felt that perceived involvement was more important.

> even if it's only an illusion (involvement), which in many circumstances it is, it is the perception that matters (CAG p20; advocate group)

Perceived professional-consumer agreement

Participants consistently placed a great value on feeling that they agreed with their doctor over the choice of treatment. Many commented that if they disagreed with a suggested treatment they simply would not take it.

> he said "You're depressed" and I said "I'm not". So he chucked these antidepressants at me and I went home …… I chucked them in the bin. (Cf p21; primary care-based)

Satisfaction with the way a decision is made

Perhaps one of the contributions to professional-consumer agreement lies in the way a decision is made. Participants felt that they certainly could not give informed consent to a treatment decision if they were not provided with sufficient information (see below) and the opportunity to discuss issues which arise. If these 'competencies'[19,20] are evident, then consumers would be likely to be satisfied with the decision-making process.

> I would hate to see a situation where you couldn't actually go into see a doctor and discuss it with him. If you had to go in and say "I've read all the information, I think I've got that wrong with me, what can you give me for it?", it would be incredible (Sw p27; primary care-based)

An important factor in the way decisions are made is having sufficient time. Many participants commented on dissatisfaction when discussions are rushed, and that the professional should be trying to avoid giving the impression of being rushed, even if this is the reality.

> most of us want time to be able to spend on that kind of face to face contact …. a discussion, decision making but in the real world; perhaps we're looking for rather more than is available (Ne p5; primary care-based)

Certainty that best decision is made

Participants felt in some cases that an important outcome was feeling certain that the best decision for them personally had been made. This may supersede preferences for involvement in decisions, but may also be the product of a successful decision-making process, where involvement is critical.

> if I come into a room and a man gives me the feeling that he knows what he's doing, I would probably take his advice, rather than him saying to me, what do you think, or have you anything to add to this (PS p13; primary care-based)

Opportunity to involve others

A final category in this theme concerned the opportunity to continue the decision-making process outside the consultation. Participants consistently placed value on this, and described a number of other people who they might like to involve. These included other family members, though apparently even more so other professionals in the team, and voluntary or self-help support groups for consumers.

> the GP could say to the patient, right I think HRT might be beneficial to you but there are other options, I'll get my nurse to explain them to you and then if you've got any further questions or whatever conclusion you come to then I will see you and we'll go ahead (PA p11; advocate group)

Content of discussions in a consultation

Options and choices specified

Concerning the precise content of discussions, participants felt that as consumers they would want to be made aware of the full range of treatment options or choices available.

> I would like to know myself. I know what I'm going through and I say look, this is happening already, I know what's happening to me, then give me the alternatives (Cf p5; primary care-based)

Many recalled scenarios in which they had *not* been presented with the full range of options – in effect the professional had, therefore, restricted their choice – and this was viewed negatively.

Information provision

Participants described many aspects of the information which they would value in a consultation. They wanted the information to be 'individualized' (i.e. the most pertinent available) for their situation. They wanted 'complete' information regarding these most pertinent issues, indicating that they felt they had not been provided with all the necessary information (particularly about harms of treatments) upon which to base a decision. Truly 'complete' information is probably unrealistic, but many participants viewed this as meaning sufficient information to make a decision. They wanted the information to be honest, accurate and clearly presented. Some recognized the capacity of information formats to manipulate decisions made and that this should be avoided, and they wanted a meaningful interaction over the information. Unnecessary repetition of information should also be avoided, and above all, participants wanted to feel that they had understood what was discussed in a consultation.

> I would want to feel that it was honest and complete, taking into account my situation, personal (CAG p18; advocate group)

> it's important to you if the doctor is listening to what you're saying rather than just giving you information (Cf p18; primary care-based)

Support materials

Because of the potential for large amounts of information to be imparted, the value of supplementary leaflets and tapes was highlighted. A further possibility concerned the potential value of having a tape-recording of the consultation to

be able to listen to later and revisit the issues raised. Even if further information was not provided during or as a result of a consultation, participants felt that awareness of other information sources that could be explored was also of value to consumers.

> I think it's good to have a small summary on paper of what you've decided so that when you go home you really know what you've decided, because sometimes you're not sure afterwards (CAG p17; advocate group)

> a tape recording of ordinary GP consultations would be a good idea (Ne p11; primary care-based)

Review arrangements

Participants felt it was important that some part of the discussions should address follow-up plans. Value was placed on the feeling of security that a clear follow-up plan provided. Related to this, participants also described how it was important for the consumer to feel that they can approach the professional again to review the condition or chosen treatment.

> the follow up is just important as the shared decision making. I think that really should be an essential part of the decisions (PS p17; primary care-based)

Health outcomes

The final theme of outcomes volunteered by participants concerned actual patient-based health outcomes. One such theme was anxiety or similar feelings of fears being reduced, or the converse, of being reassured. The latter was a major goal for consumers. In general, however, it was noticeable how little emphasis participants placed on improvement in actual health outcomes *per se*. There was also little recognition that adherence to chosen treatments was of importance to consumers. This was viewed (often disdainfully) as something of only 'medical interest'.

> we want to feel reassured when we come out, more than anything we want to be reassured that he understands exactly how you feel, not just to go in and tell him and he's writing a prescription out and you haven't finished what your saying, I think you need reassurance (Ne p6; primary care-based)

> compliance is a real issue for the medical profession, but it isn't something that a lay public would automatically have on top of their list (CAG p42; advocate group)

Discussion

In this research, important outcomes of consultations for consumers included feeling respected and perceiving that they had contributed meaningfully to the process and discussions. The participants also wanted to feel that consultations and their care had been 'individualized' for them, and that complete and honest information had been provided. Other valued outcomes included the consumers perceiving that they were involved in decision-making, even leading the decision-making. Perhaps out of a sense of reality, recognizing that professionals will frequently exert a large degree of control through their access to the specialist knowledge base ('power asymmetry'),[21] many participants felt that actual involvement in the decision-making was less important than the level of *perceived* involvement. They also recognized that actual involvement and preferred levels of involvement would be 'context dependent', varying according to the nature, severity and chronicity of their condition. Thus, for example, more paternalistic styles might be more preferred in situations where the illness is more severe or acute, but the same individual might prefer greater involvement in decisions about more long-lasting illnesses and treatments. Participants placed a high value on 'appropriate involvement' according to the circumstances, and it seems that some role negotiation, however brief, or even implicitly rather than explicitly, should take place at the beginning of every consultation. In contrast to these 'patient-based' outcomes[22] and comments on the process of consultations, these participants did not place a high value on compliance and other behavioural measures.

The strength of this research is its use of purposeful sampling and a qualitative method. In doing so, it identified several issues of importance to consumers in their dealings with health-care providers, and a broader range of

issues than has been addressed in other current research as will be described below. Previous methodological work on patient-based outcomes[22] has generally not begun with such exercises to identify consumers' views. If consumers have been consulted then this may only have been a small contribution to the process,[14] or to express views on items generated first by other 'experts'.[23] Furthermore, the ways such views have been collated have limitations. Seeking consumer views of potential items by questionnaire response[14,23] restricts the range of potentially important items at the outset, whereas our method has allowed consumers to identify any outcome they view as important. In particular, the participants were able to feed off each other's experiences in arriving at a view or range of views in the group.

These other methods also beg questions about who is most qualified to be the 'expert' in generating items or outcomes – the professional or the consumer. The focus on communication and discussion between professionals and consumers is set in a paradigm which is intrinsically 'patient-centred'.[24,25] In this paradigm it seems natural to regard the consumer as the 'expert', and the arbiter of which items or outcomes are important.

In contrast to the strengths of the method used here, there are weaknesses. The method does not allow us to comment on the relative importance of the outcomes noted with any degree of generalizability. We note also that the qualitative method itself (using focus group interviews) may have biased results towards certain topics. These may be those of general interest or comfort in discussing in a group situation. Other methods, such as one-to-one interviews with consumers may generate a different range of outcomes, perhaps with greater emphasis on the issues which are most pertinent or sensitive to the individual concerned.

Comparison with existing literature

However, even if other outcomes and issues might be identified by other methods, the range of outcomes identified here has its own credibility. We can compare the results of this study with the outcomes reported in the established literature of this field (see Table 2). Many of the aspects identified by participants were consistent with the 'affective' outcomes on which current research focuses.[5,6] These included reduced anxiety and allaying fears, certainty over the choice made and confidence in the doctor (or other professional) concerned, and satisfaction with the way in which decisions were made or information provided. Some of these issues are addressed by existing scales such as the Decisional Conflict Scale[10] or the Satisfaction with Decision scales.[7–9]

Importantly, however, further affective outcomes were also identified. These included feeling reassured that they were being supported by professionals in dealing with their condition, and comfort that there was continuity of care from professionals and opportunity to involve others where appropriate. The scope of outcomes suggested by these participants appears much broader than in the current literature.

Participants appeared to value involvement and support of others such as allied professionals (nurses, counsellors) and consumer groups more than other family members, though this may not be a true reflection of views in general owing to the purposeful sampling for this study. These British participants expressed strong preferences for there to be definite management plans, agreed by professionals and

Table 2 Types of outcomes reported in risk communication literature[5]

Theme	Category
Cognitive	1. Patient's knowledge change after intervention 2. Accurate risk perception
Behavioural/ physical	1. Compliance (intended or actual; with treatment or uptake of information package)
Affective	1. Anxiety ratings (general, state and trait) 2. Satisfaction 3. Certainty about option chosen 4. Assessment of decision making process 5. Assessment of information given

patients, and clear follow-up plans, perhaps backed up by summary material or audio-taped information. This strong call for ongoing support is understandable, but may suggest that approaches which seek to enhance autonomy[26] and 'patient enablement'[27] have some way to go before matching consumer expectations or preferences. Professional strategies for consultations must be flexible enough to meet the variable preferences of consumers for involvement in their health-care decisions. Clearly, this may be context-specific to the British or perhaps other publicly funded health-care systems, or to the primary-care setting, and this requires further evaluation.

Some cognitive outcomes[6] were identified (e.g. comprehension of information presented), but other cognitive and behavioural outcomes frequently addressed in research[5] were not volunteered by participants as important to consumers. Such outcomes included accurate risk perception, and adherence to treatment schedules or reducing risk behaviour (e.g. smoking). Many participants recognized that professionals value these outcomes, but viewed these as more peripheral to the individual concerned than the affective measures described above.

Conclusion

This study firstly confirms that many of the outcomes addressed in shared decision-making research are important to consumers. These included perceived involvement in decisions and professional-consumer agreement. They also included anxiety, satisfaction with the way decisions are made and certainty that the best decision has been made, for which validated assessment scales exist.[7,8,10] Secondly, however, these participants did not identify some outcomes addressed regularly in the literature, such as knowledge and accurate risk perception. This suggests that the emphasis on these outcomes to date may have been misplaced for a research field which aims to be 'patient- or consumer-centred'.[25]

Thirdly, these participants identified new aspects which they regard as important. These included feeling respected and making a meaningful contribution to the discussions, as well as the opportunity to involve others, the availability of extra information sources, and clear arrangements for review of the treatment decision. Fourthly, these participants actively rejected adherence to treatment or health behaviour change as important outcomes. Such outcomes have been reported most frequently of all in the literature to date.

It seems fundamental that research in this topic area should evaluate the effects of training or other interventions in terms of the outcomes of most importance to consumers. We do not suggest a complete re-alignment of the outcomes measures for research, but the data in this study demonstrate a clear need to re-visit the types and range of outcomes for assessment. Further work should be conducted to confirm the areas of most importance to consumers. The generalizability of such findings or their specificity to certain countries or health-care systems must be addressed as part of this. When such findings are available, an informed discussion will be possible to decide whether consumers' or professionals' values and interests take precedence in driving and designing research for the future.

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Appendix 1 Content of focus group interviews

Introductions, and scene setting regarding research project and the value of participants views, particularly to inform further research
Stimulus materials
Overview of 'shared decision-making' including: paternalistic, shared and informed choice models of consultation; identification of advantages and disadvantages of treatments as an issue for later discussion
Audio-tape of consultation in which hormone replacement therapy is discussed, including information about its harms and benefits
Semi-structured discussion
Prompts
'What "outcomes" are most important to you?'
'What are you looking for?'
'What do you think matters most to other people?'
'What do you think other people are looking for?'
If not volunteered spontaneously by participants, explore:
'What information do you want to be given?'
'How should it be given to you?'
'How much do you wish to contribute to the decisions about treatments?'
'How do you expect to feel or want to feel at the end of a consultation?'
'How important is it to you that you stick with a chosen treatment?'
Areas volunteered by participants were explored in more depth